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Concise report

Correlation of invalidation with symptom severity and health status in fibromyalgia

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Abstract

Objective. Invalidation is a new construct in health psychology, especially in diseases with inherently invisible symptoms such as FM. It can potentially affect both the quality of life and disease severity in patients with FM. This study aimed to investigate the correlation of illness invalidation with health status and symptom severity in FM.

Methods. A total of 112 consecutive patients with FM referred to the rheumatology clinic were enrolled. Invalidation was measured by the Illness Invalidation Inventory (3*I). To measure patient status and progress of FM, the Revised Fibromyalgia Impact Questionnaire (FIQR) was used and patients' quality of life was assessed by the 12-item Short Form Health Survey (SF-12). Multiple linear regression analyses were performed and Spearman's correlations were calculated.

Results. All the patients were female and aged between 18 and 61 years. No significant differences in discounting and lack of understanding between various sources of invalidation were found. The strongest correlation was observed between FIQR symptom score and discounting by work ($r = 0.519$, $P < 0.05$). Multiple linear regression analyses revealed that only discounting from the spouse significantly predicted FIQR total scores of FM patients [$P = 0.03$ (CI 0.28, 10.64)].

Conclusion. Discounting correlated more strongly with SF-12 subscales and FIQR domains than did lack of understanding. The current study revealed that active negative social responses and the source of invalidation are important in predicting symptom severity and quality of life in FM.

Key words: fibromyalgia, invalidation, health status.

CLINICAL SCIENCE

Introduction

FM is a disease marked by chronic widespread pain accompanied by other multiple symptoms such as fatigue and sleep, cognitive or depressive disorders [1]. Patients with FM have a fundamentally invisible problem, with sensory processing being presented as chronic pain without any relevant pathological, radiological or laboratory findings. These characteristics, as well as the unknown aetiology of FM, can cause disbelief about the problems presented by patients, with the resultant misunderstanding, rejection and discounting by others and suspicion that the symptoms are overstated or have a psychological basis [2]. This is the condition recently described as invalidation [2–3].

Several studies have shown that invalidation may arise from different sources, including spouses, colleagues, health professionals and society, and it can hamper the interaction of patients with other people [4–7]. Of note, Kool *et al*. [3] showed that patients with FM experienced significantly more invalidation from different sources than did patients with RA.

It is believed that besides having a negative effect on mental well-being, invalidation could impact physical

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health and social functioning. It also decreases social support and increases social rejection [2]. Similarly, some studies have suggested that social rejection may intensify pain sensation by influencing neurons in special areas of the brain such as the anterior cingulated cortex [8–9]. Finally, in response to social rejection, patients may hide their symptoms and isolate themselves from society, which probably influences their health care [4, 7].

It is important to determine what the impacts of invalidation are on well-being, functioning and symptoms. In spite of previous studies, however, whether invalidation can alter disease impact on health status and symptom severity in FM patients is unclear. Hence this study aimed to investigate the potential impact of invalidation experiences on health status and disease severity in patients with FM.

Methods

Patients

The study was conducted on individuals who were referred to the Rheumatology Clinic of Razi Hospital from June 2012 to June 2013. All the study participants were female and were enrolled when they appeared in the clinic for their usual care. FM was diagnosed by an expert rheumatologist using the 2010 ACR preliminary criteria or the 1990 ACR classification criteria [10–11]. Individuals were excluded if they had other rheumatological diseases or were unable to read or write. Written informed consent was obtained from all the patients and demographic variables, including age, marital status, education level and duration of symptoms, were documented. This study was approved by the Ethics Committee of Guilan University of Medical Sciences.

Instruments

Invalidation was measured by the Illness Invalidation Inventory (3*I) [3]. This inventory includes eight items [discounting (five items) and lack of understanding (three items)] assessing the extent to which people experience invalidation with regard to each of five sources (spouse, family, medical professionals, work environment and social services). After permission was obtained from Dr Marianne B. Kool, the English version of 3*I was translated into Persian by two bilingual medical doctors. It was then translated back into English by a bilingual individual with a bachelor of biological sciences and a bilingual rheumatologist. Finally, the target version was compared with the original questionnaire in order to preserve the equivalence between the two versions. In this study, the Cronbach's α coefficients for all sources were at acceptable levels ($\alpha > 0.7$).

To measure patient status and the progress of FM, the validated Persian version of the Revised Fibromyalgia Impact Questionnaire (FIQR) was used. This is divided into three linked sets of domains as in the original FIQ: function, overall impact and symptoms [12–14]. In the present study, Cronbach's α was 0.87 for the FIQR, indicating acceptable levels of internal consistency. Finally, quality of life was assessed by the validated Persian version of the 12-item Short Form Health Survey (SF-12) including eight dimensions: physical functioning, physical role, social role, emotional role, bodily pain, general health, vitality and mental health [15].

Statistical analysis

In univariate analysis, Spearman's correlation coefficients were calculated to examine the association of invalidation scores with the FIQR domains and also with the SF-12 subscales. Multiple linear regression (backward method, removal level = 0.1) was used to obtain insight into the correlations between variables. Significance level was set at $P < 0.05$ and all statistical analysis was carried out using SPSS for Windows version 17.0 (IBM, Armonk, NY, USA).

Results

A total of 112 consecutive patients were enrolled. All the patients were female, aged 18–61 years [mean 39 years (S.D. 10)]. Mean disease duration was 47.6 months (S.D. 62.4). Sixty per cent of patients were educated at secondary or tertiary level. Since 80% of subjects were housewives, only 22 patients completed the last two parts of the 3*I. Discounting and lack of understanding scores for each source were reported as the average of the scale items. Scores for items 3, 5 and 8 were first reversed into the direction of lack of understanding.

The mean discounting scores for spouse, family, medical professionals, work environment and social services were 1.95 (S.D. 0.85), 1.98 (0.86), 1.64 (0.79), 1.74 (0.85) and 1.15 (0.23), respectively. No significant difference was found between the five sources ($P = 0.06$). Similarly, the mean lack of understanding scores for spouse, family, medical professionals, work environment and social services was 1.91 (S.D. 1.12), 1.60 (0.75), 2.07 (1.31), 1.85 (0.96) and 1.16 (0.28), respectively. Again, no statistical difference between these scores was found ($P = 0.07$).

The frequency of FM patients who sometimes (>2.5–3.5) and often/very often (>3.5–5) experienced discounting by their spouse, family, medical professionals, work and social services was 26.7%, 27%, 15.5%, 18.1% and 0%, respectively. Likewise, the frequency of FM patients who sometimes and often/very often experienced lack of understanding was 23.8%, 11.8%, 31.1%, 27.2% and 1.4%, respectively.

Spearman's correlation coefficients revealed some significant correlations between discounting/lack of understanding and FIQR scores (total, function, overall and symptom scores) (Table1). The strongest correlation was observed between the FIQR symptom score and discounting by work ($r = 0.519$, $P < 0.05$). Overall, discounting correlated more strongly with FIQR domains than did lack of understanding.

Spearman's correlations of the discounting and lack of understanding invalidation sources and subscales of the SF-12 are shown in Table 2. Discounting by medical professionals and work environment correlated more strongly

Table 1 Spearman's correlations of invalidation with FIQR domains

	FIQR function score	FIQR overall score	FIQR symptom score	FIQR total score
Discounting				
Spouse	0.013	0.182	0.316**	0.195
Family	0.016	0.197*	0.297**	0.217*
Medical professionals	0.103	0.372*	0.213	0.263
Work environment	0.056	0.465*	0.519*	0.450*
Social services	−0.056	0.237*	0.120	0.109
Lack of understanding				
Spouse	−0.157	−0.028	0.030	−0.059
Family	−0.147	0.071	0.045	0.023
Medical professionals	−0.098	0.356*	0.318*	0.252
Work environment	−0.278	0.343	0.202	0.202
Social services	0.048	0.128	0.083	0.093

*$P < 0.05$ (two-tailed), **$P < 0.01$ (two-tailed). FIQR: Revised Fibromyalgia Impact Questionnaire.

with subscales of SF-12 than other sources. Discounting by these two sources also inversely correlated most strongly with the mental health ($r = -0.363$, $P < 0.05$) and social functioning ($r = -0.610$, $P < 0.01$) items of the SF-12. No significant correlation was found between lack of understanding by spouse, family, work environment or social services and SF-12 items.

Finally, unadjusted multiple linear regression analyses between the FIQR total score and different sources of invalidation revealed that only discounting by spouse could significantly predict the FIQR total score [$b = 5.46$, $P = 0.03$ (95% CI 0.28, 10.64)]. Adjusted linear regression analyses by age, education level, time since diagnosis and work status also showed that discounting by spouse could be a significant predictor of the FIQR total score [$b = 10.09$, $P = 0.002$ (95% CI 4.01, 16.18), partial correlation = 0.519]. In the final adjusted model, lack of understanding by spouse and age were also predictors of the FIQR total score, but neither was statistically significant ($P = 0.057$ and $P = 0.093$, respectively).

Discussion

Our study revealed the clinical relevance of invalidation in symptom severity and health status of patients with FM. The amount of invalidation arising from spouse and colleagues was higher than that from medical professionals and social services. Discounting correlated more closely with disease impact and quality of life than with lack of understanding. In addition, more discounting and lack of understanding were associated with higher FIQR scores. There was a negative correlation between discounting and mental health, physical and social function. This indicates that more discounting may be associated with worse mental well-being and worse physical and social functioning.

Invalidation is a new concept and evidence of its harmful effects on health status, pain and symptoms in FM is very scant [3, 16]. The newly developed 3*I captures both active negative social responses (denying, lecturing, overprotecting) and positive social interactions (supporting, acknowledging). These two dimensions of invalidation reflect discounting and lack of understanding, respectively, as higher-order constructs of the 3*I [3].

This study revealed that discounting is correlated more strongly with poor social and physical functioning as well as impaired mental health than lack of understanding. This is in line with previous studies showing that negative social interactions might have stronger effects on health than positive social interactions [16–17].

We also found that the more invalidation was experienced by patients, the higher the FIQR scores, the greater the disease impact and the greater the symptom severity. Furthermore, discounting correlated more strongly than lack of understanding with higher FIQR scores and impact of FM on life. In fact, these results reflect that discounting may have negative implications for physical health and pain. It could also be a predictor of poor physical and mental health along with disease severity in FM.

Notably, discounting expressed by a spouse was the only variable that could predict the FIQR total score and symptom intensity in multiple linear regression analyses. For each unit increase in discounting by a spouse, the total FIQR score rose approximately 5–6 units, and even up to 10, in the adjusted model. This finding showed that different sources of invalidation had different impacts on patients. As could be expected, the patient and spouse shared daily life experiences, thoughts and feelings and had more empathy [18]. So the invalidation expressed by a spouse may have a greater impact on a patient's symptoms and disease outcome. However, it is not clear whether the subjects responded well to the intended content of questions in the study questionnaires. In the same way, we are unable to explain what roles cultural factors might play when people are expressing their attitudes, emotions and invalidation experiences.

There are also some limitations in the present study. Only female subjects were recruited and therefore the results of this study cannot be generalized to men with FM. Furthermore, we did not evaluate our patients in a primary care setting, thus they probably do not reflect the general population of FM patients. Moreover, as eighty percent 80% of our patients were not employed, a considerable number of patients did not complete the last two source categories (work environment and social services). Therefore caution should be exercised in interpreting the results of these domains. It also needs to be highlighted that in this study mood disorders were not evaluated, and they might have influenced invalidation.

Research on invalidation is relatively new. It is especially important to pay attention to the impact of invalidation by focusing on its effect on pain, disease severity and outcome. This is the first study that has attempted to clarify the clinical effects of invalidation on disease impact and severity. Our findings suggest that active negative social

Table 2 Spearman's correlations of invalidation sources with subscales of the SF-12

	SF-12 items							
	PF	PP	BP	GH	VT	SF	EP	MH
Discounting								
S	−0.134	0.108	0.098	−0.142	−0.155	−0.239*	0.139	−0.249*
F	−0.069	0.051	0.087	−0.245*	−0.250*	−0.273**	0.051	−0.069
MP	−0.347*	0.235	−0.228	−0.211	−0.343*	−0.313	−0.003	−0.363*
WE	−0.467*	0.181	0.122	−0.214	−0.241	−0.610**	0.229	−0.037
SS	−0.049	−0.280*	0.213	−0.039	−0.054	0.079	−0.003	0.025
Lack of understanding								
S	0.100	−0.011	0.065	−0.025	−0.076	−0.119	−0.108	−0.205
F	0.108	−0.063	0.165	−0.192	−0.143	−0.112	−0.112	−0.015
MP	−0.054	0.119	−0.052	−0.129	−0.401*	−0.371*	−0.080	−0.032
WE	0.095	−0.022	−0.083	−0.402	−0.373	−0.173	0.228	0.101
SS	−0.312**	−0.075	0.109	−0.064	−0.120	0.026	−0.067	−0.046

*$P < 0.05$ (two-tailed), **$P < 0.01$ (two-tailed). SF-12: 12-item Short Form Health Survey; PF: physical functioning; PP: role functioning difficulties caused by physical problems; BP: bodily pain; GH: general health; VT: vitality, energy; SF: social functioning; EP: role functioning difficulties caused by emotional problems; MH: mental health; MP: medical professionals; SS social services; WE: work environment; S: spouse; F: family.

responses and the source of invalidation are important in predicting symptom severity and quality of life in FM. These results will be influenced by the general acceptance of FM by the medical profession in Iran.

It remains to be determined how stable the concept of invalidation will be over time. It seems that invalidation may be managed with cognitive-behavioural therapies (e.g. cognitive restructuring) and educating people about FM [19]. But there is no study targeting the management or outcome of invalidation.

We emphasize the need to pay attention to invalidation in the general assessment and treatment adherence of patients with FM. Of note, patients usually have diverse complaints and may undergo exhausting diagnostic and therapeutic processes because of their symptoms. It seems that physicians' perception of invalidation, especially physicians involved in patient care, could be a clue for the diagnosis of FM. In fact, since it is not clear whether invalidation assessment could be advantageous in the diagnosis or classification of FM, future research focusing on this issue seems to be the next step.

Rheumatology key messages

- Invalidation is a newly introduced concept in FM that correlates with disease severity.
- Some dimensions of invalidation and sources of its experience are more important in prediction of health status in FM.

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